


# Incorporating the Patient into Quality Metrics – What Do Patients Want?



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# Incorporating the Patient into Quality Metrics – What Do Patients Want?

**Alice**



**Gary**



# The Institute of Medicine Core Principles

Health care that is:

- safe
- effective
- ***patient-centered***
- timely
- efficient
- effective



Institute of Medicine Committee on Quality of Health Care in America.  
Crossing the Quality Chasm: A New Health System for the 21st Century.  
Washington, DC: National Academies Press, 2001



# Disease Centered Care

## guidelines



# Comparison of Traditional Disease-Specific and Goal-Oriented Outcomes

Comparison of Traditional Disease-Specific and Goal-Oriented Outcomes.\*

Measurement Domain	Examples of Diseases	Traditional Outcomes	Goal-Oriented Outcomes
Survival	Cancer, heart failure	Overall, disease-specific, and disease-free survival	None if survival not a high-priority goal; survival until personal milestones are met (e.g., grandchild's wedding)
Biomarkers	Diabetes, COPD	Change in indicators of disease activity (e.g., glycated hemoglobin level, CRP level, and pulmonary-function tests)	None (not a meaningful outcome observed or felt by patient)
Signs and symptoms	Heart failure, COPD, arthritis	Inventory of disease-specific signs and symptoms (e.g., dyspnea, edema, and back pain)	Symptoms that have been identified as important by the patient (e.g., control of dyspnea or pain sufficient to perform an activity such as bowling or walking grandchild to school)
Functional status, including mobility	Cancer, heart failure, COPD	Usually none or disease-specific (e.g., Karnofsky score, NYHA functional classification, and 6-minute walk test)	Ability to complete or compensate for inability to complete specific tasks identified as important by the patient (e.g., ability to get dressed without help)

\* COPD denotes chronic obstructive pulmonary disease, CRP C-reactive protein, and NYHA New York Heart Association.

**Reuben DB, Tinetti ME. N Engl J Med 2012;366:777-779.**

# Types of Quality Measures

## Structural

- e.g., EHR use

## Process

- e.g., % of patients receiving preventive services, % of patients at HgBA1C goal

## Outcome

- e.g, mortality, complications, adverse events
- Considered the gold standard
- Risk adjustment is needed to account for differences in population characteristics

Congratulations!  
The tests were negative,  
everything is perfectly  
alright!

My whole life  
is affected!

I cannot  
sleep

I cannot bend  
over or exercise

I cannot eat  
and drink  
whatever I like



# Patient Reported Health Status

**Definition: Reflection of how a patient perceives their symptom burden, functional limitations, and the impact of their health on their quality of life.**

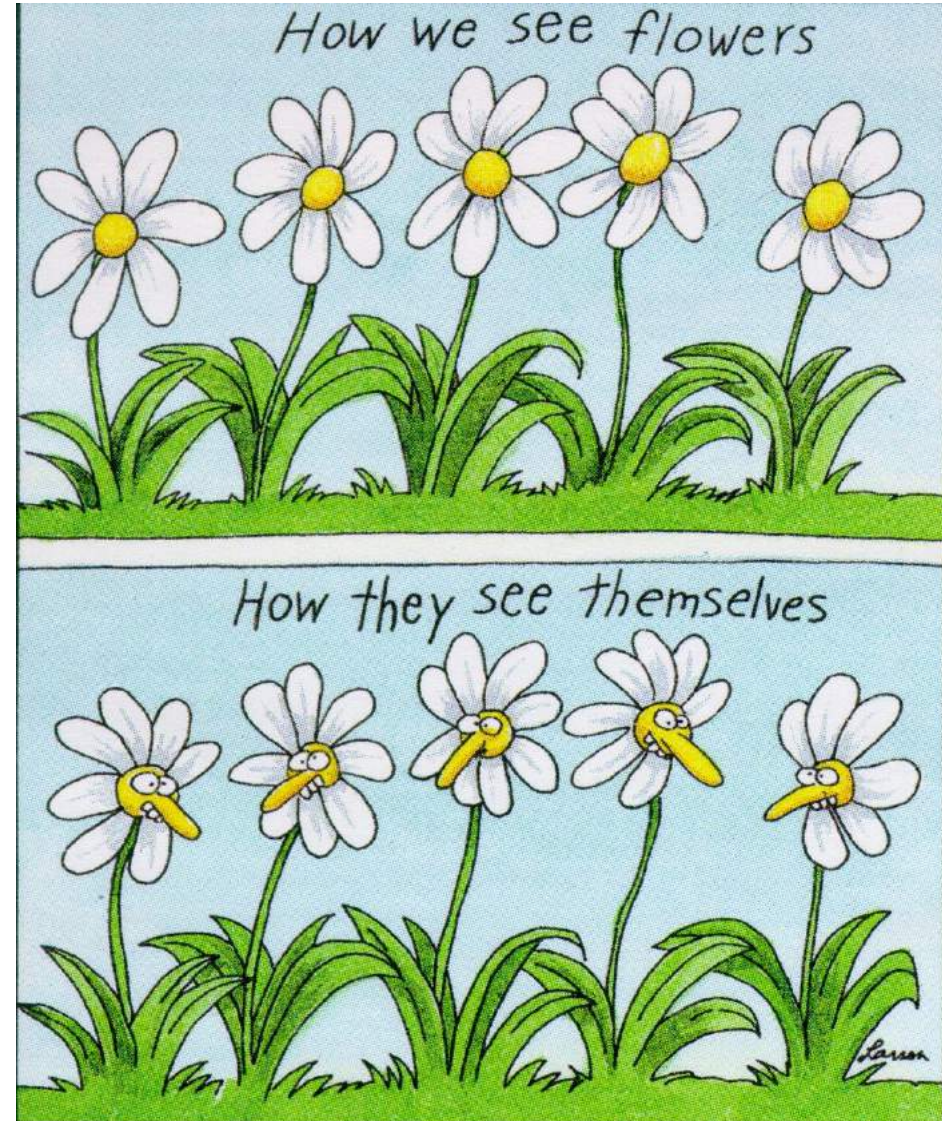
- *Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995 January 4;273(1):59-65.*
- *Rumsfeld JS, Alexander KP, Goff DC, Jr. et al. Cardiovascular health: the importance of measuring patient-reported health status: a scientific statement from the American Heart Association. Circulation 2013 June 4;127(22):2233-49.*



# Why We Need To Formally Measure Health Status?

There is a large discrepancy between physician-rated and patient-rated symptom burden and functional limitation

*Calkins Ann Intern Med 1991, Guyatt J  
Chron Dis 1985, Kivenin Age Ageing  
1998*



# Patient Reported Outcome: Definition

A **patient-reported outcome** or PRO is a method or questionnaire used in a clinical trial or a clinical setting, where the responses are collected directly from the **patient**.

## PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment

# Can health status measures be used to monitor patients in clinical practice?

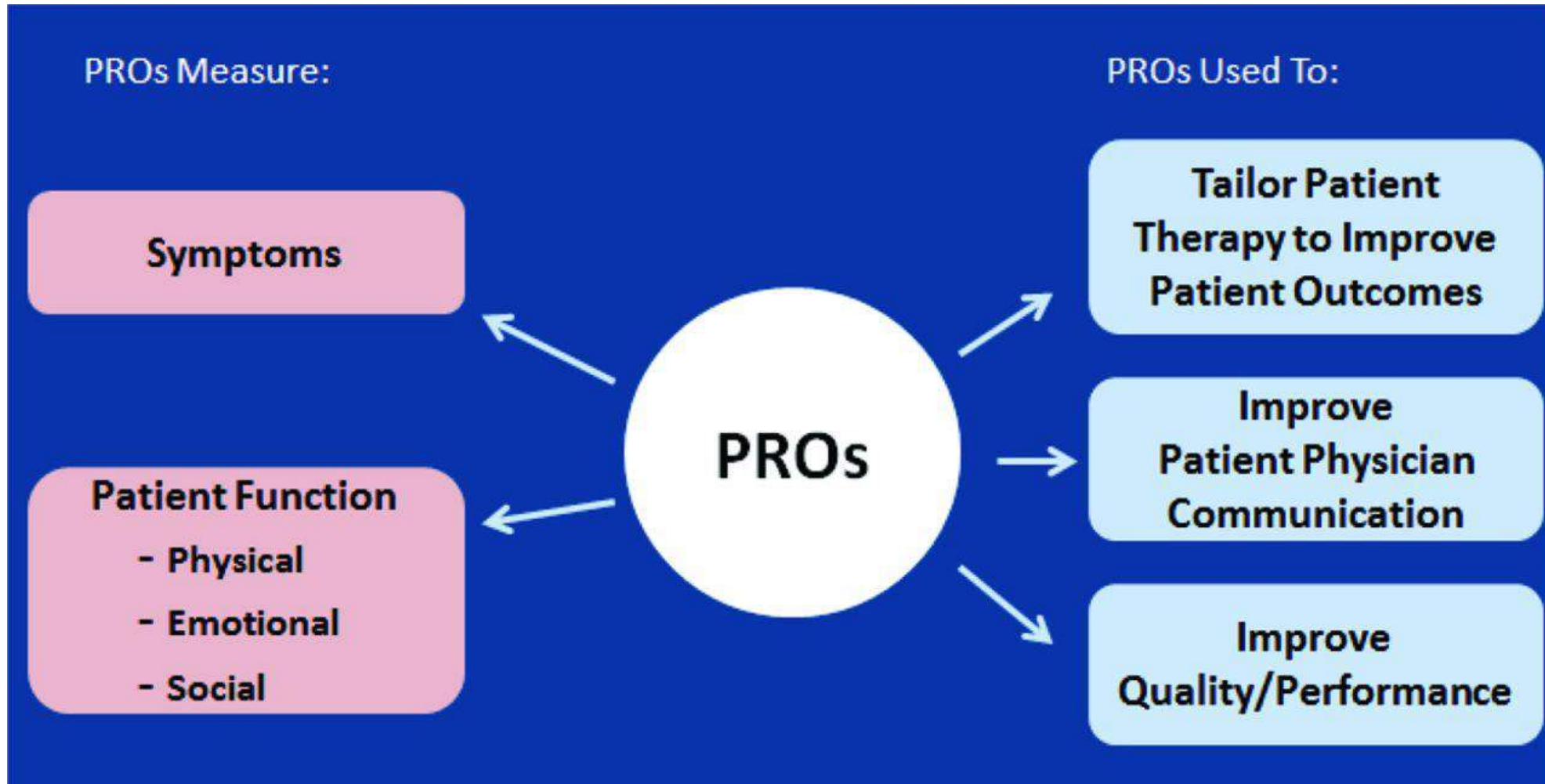


Inform treatment  
and intervention decisions



Improve patient outcomes

# Integrating PROs into Clinical Practice



# Difference Between Clinical Measures and Self-Reported Measures

**Clinical measures** include physiologic measures that require professional knowledge to interpret and clinician judgments that come from interviews and observations of patients.

**Self-reported measures** of health and quality of life often have more meaning to the persons who are affected by disease, are undergoing treatments, or are trying to restore or maintain health.

# Outcomes that are not Patient Reported

- avoidable readmissions
- hospital-acquired infections
- mortality
- blood pressure
- hemoglobin A1c levels in diabetics
- MACE

# Examples of PRO Surveys

- Short-Form 36 (SF-36), which measures overall physical and mental health status without disease-specific questions
- Seattle Angina Questionnaire (SAQ)
- Minnesota Living With Heart Failure (MLWHF)
- Kansas City Cardiomyopathy Questionnaire (KCCQ)

# PROs and Cardiology

In the past 15+ years, there has been a trend to incorporate patient acquired and patient reported data into the practice of cardiology

Reasons include:

1.) **Growing population of patients with stable chronic disease**

-More episodic visits when symptomatic, but continuous surveillance of disease is needed

2.) **Rapid growth of HIT**

Digital technology allows patients to measure and monitor health status through self measures (blood pressure, weight), or through attached/wearable monitors

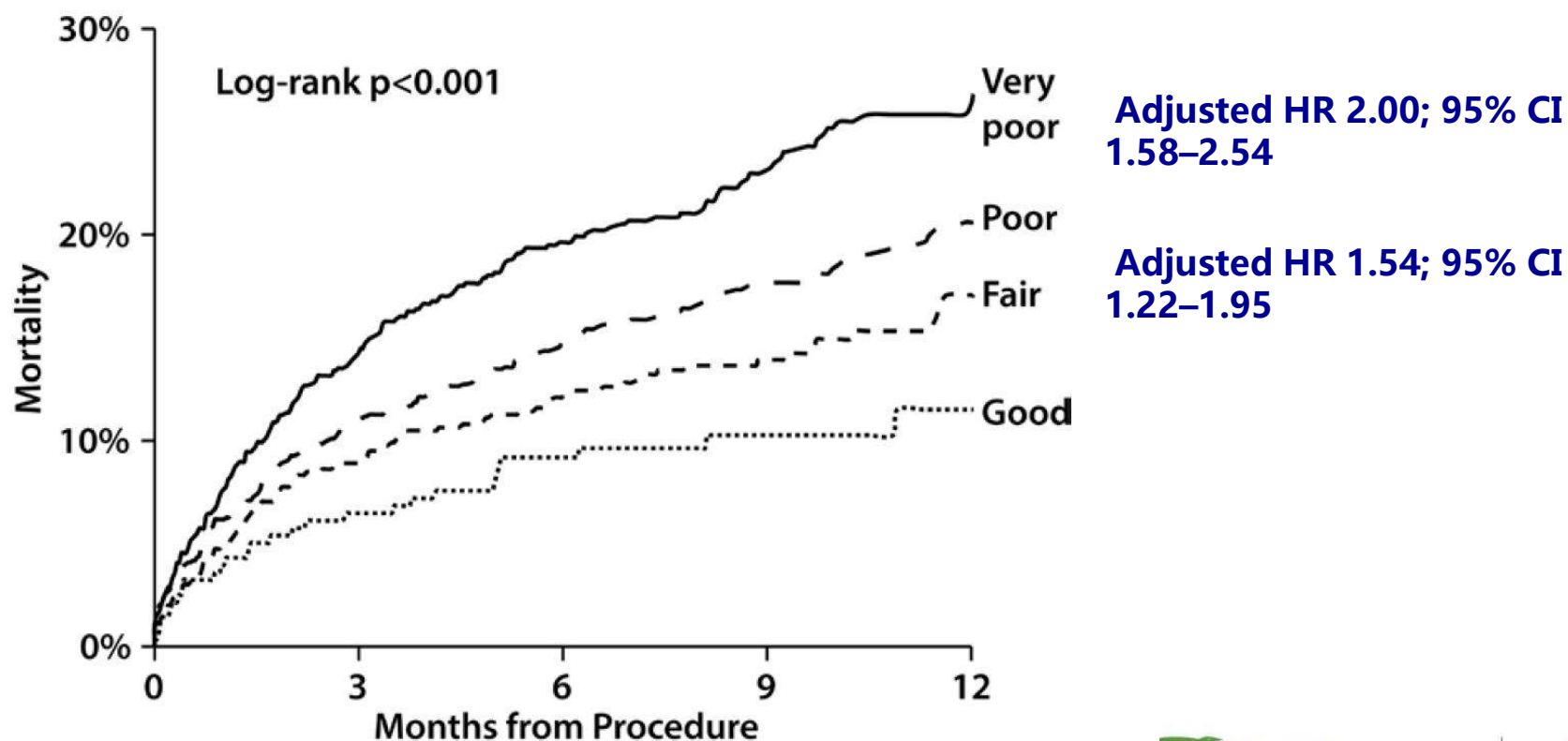
3.) **Increased importance of perceptions of care and QoL**

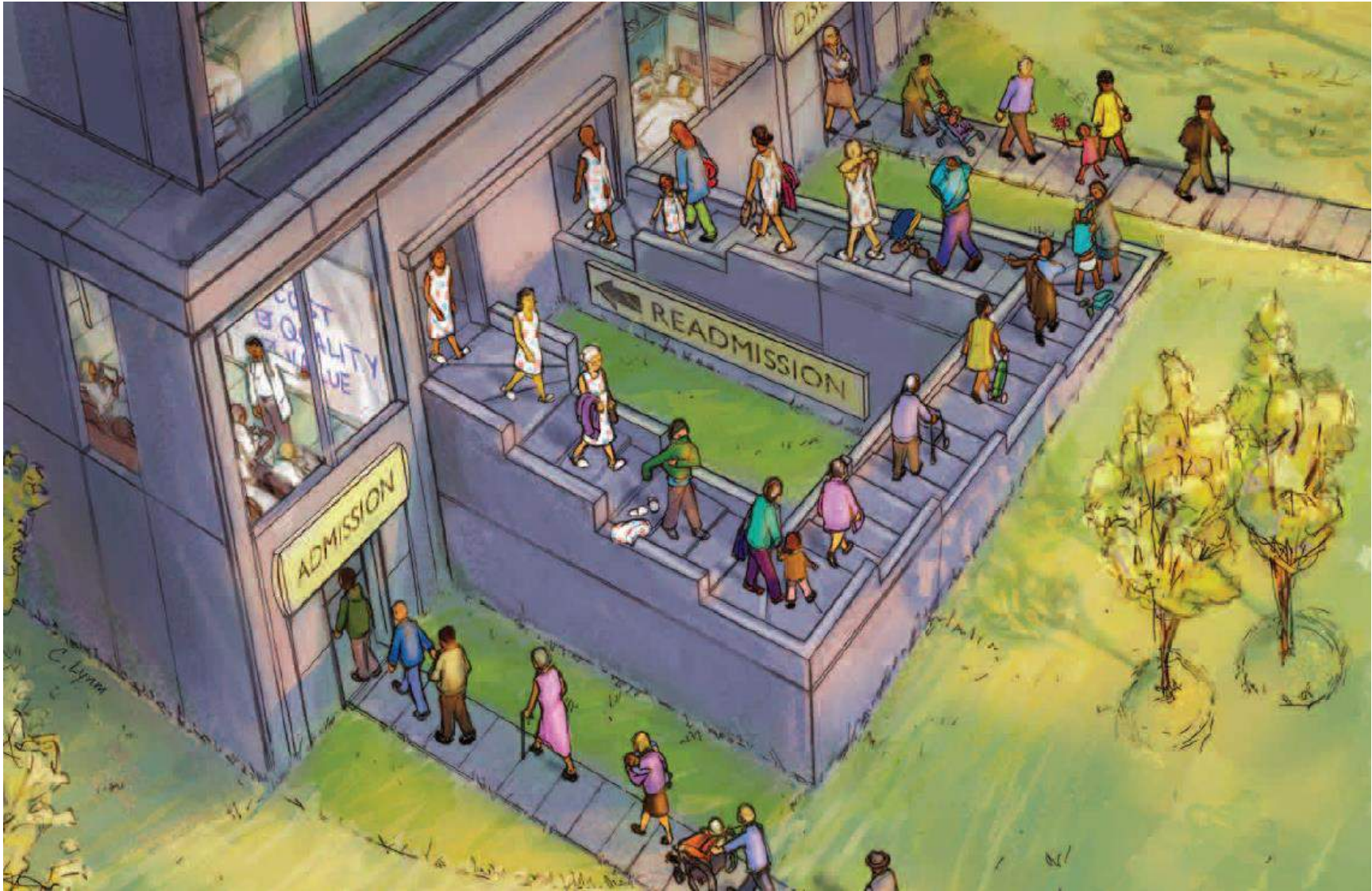
4.) **Future reimbursement models**



# Association of Patient-Reported Health Status With Long-Term Mortality After Transcatheter Aortic Valve Replacement

Report From the STS/ACC TVT Registry





# What does the patient say?

## Patients with HF who were readmitted within 30 days to the medical or cardiology service at UCLA

- 68 patients reported that their readmission was not preventable, 26 reported that it was preventable, and 4 were undecided.
- Compared with patients reporting nonpreventable readmissions, patients who reported preventable readmissions or who were undecided were more likely to report:
  - being discharged before being ready (69% vs 13%,  $P < .001$ ), not having all concerns addressed before discharge (67% vs 15%,  $P < .001$ )
  - being less satisfied with the discharge team on a scale of 1 to 10 (mean, 6.3 vs 8.0;  $P = .01$ )
  - not having a follow-up appointment with the primary care physician or a specialist scheduled at discharge (31% vs 12%,  $P = .03$ )

# Major contributors to positive and negative experiences in people's health care

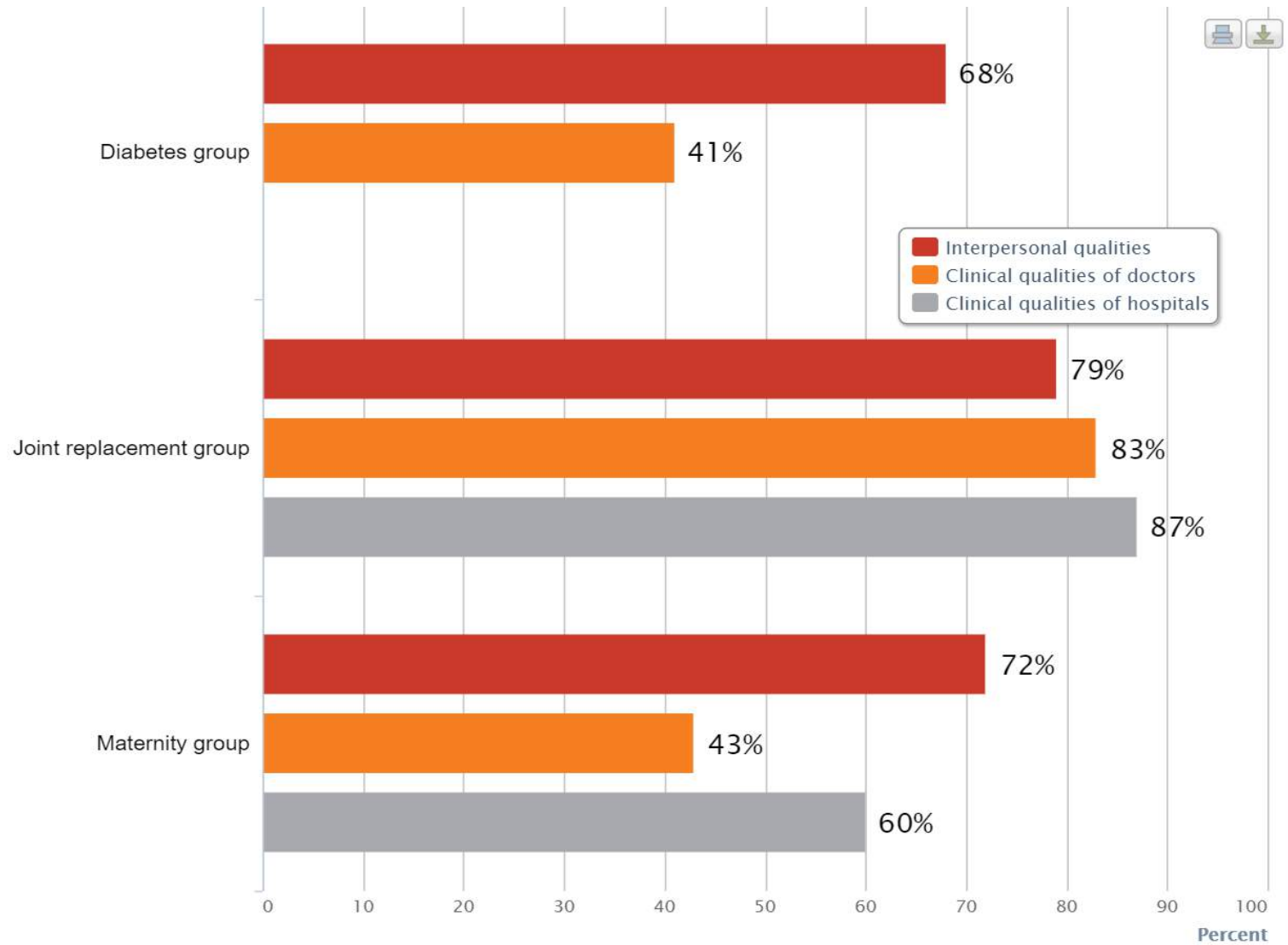
People were randomly selected at four types of settings in Washington, DC: coffee shops, metro stops, senior centers, and community centers.

- To the first question, about positive and negative experiences with health care, all respondents (100%) cited examples of an interaction with their **doctor**.
- Some (47%) cited additional examples of interacting with **other health care professionals**.
- None gave examples of interactions with insurance companies, hospital administration, legislators, or other health care stakeholders.
- All (100%) also mentioned their interaction with their **doctor** in response to the second question, about how to most improve health care in the U.S. To this question, none cited the role of other health care stakeholders or proposed health systems changes except in relation to the interaction with their doctor.

Wen LS, Tucker S. What do people want from their health care? A qualitative study. J Participat Med. 2015 Jun 18; 7:e10.

# Average percent of people who say the various interpersonal or clinical qualities of doctors or hospitals are very important for high-quality care, by group.

Nationally representative surveys of people who have experienced one of three common types of health care for which quality and costs can vary: type 2 diabetes care, joint replacement surgery and maternity care.



# Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness

## Joanne's Story

**The things Joanne wants her healthcare team to know about her:**

"I want to stay in my home as long as possible."

"I want to spend time doing things I love, being with people important to me."

**What Matters Most to Joanne at this time?:**

"I want to stay in my house as long as possible."

**Joanne has stated the following related goals and plans:**

**Focus 1 Description:** "Never give up hope of staying home"

**Focus 2 Description:** "I want to get off or take less pain medications."

**Focus 3 Description:** "I want to have more energy and stamina."

**Focus 4 Description:** "I always hope to make a trip to visit friends & family, here and in Europe."

**Focus 5 Description:** "Protect my assets and get my affairs in order to leave some money for my family."

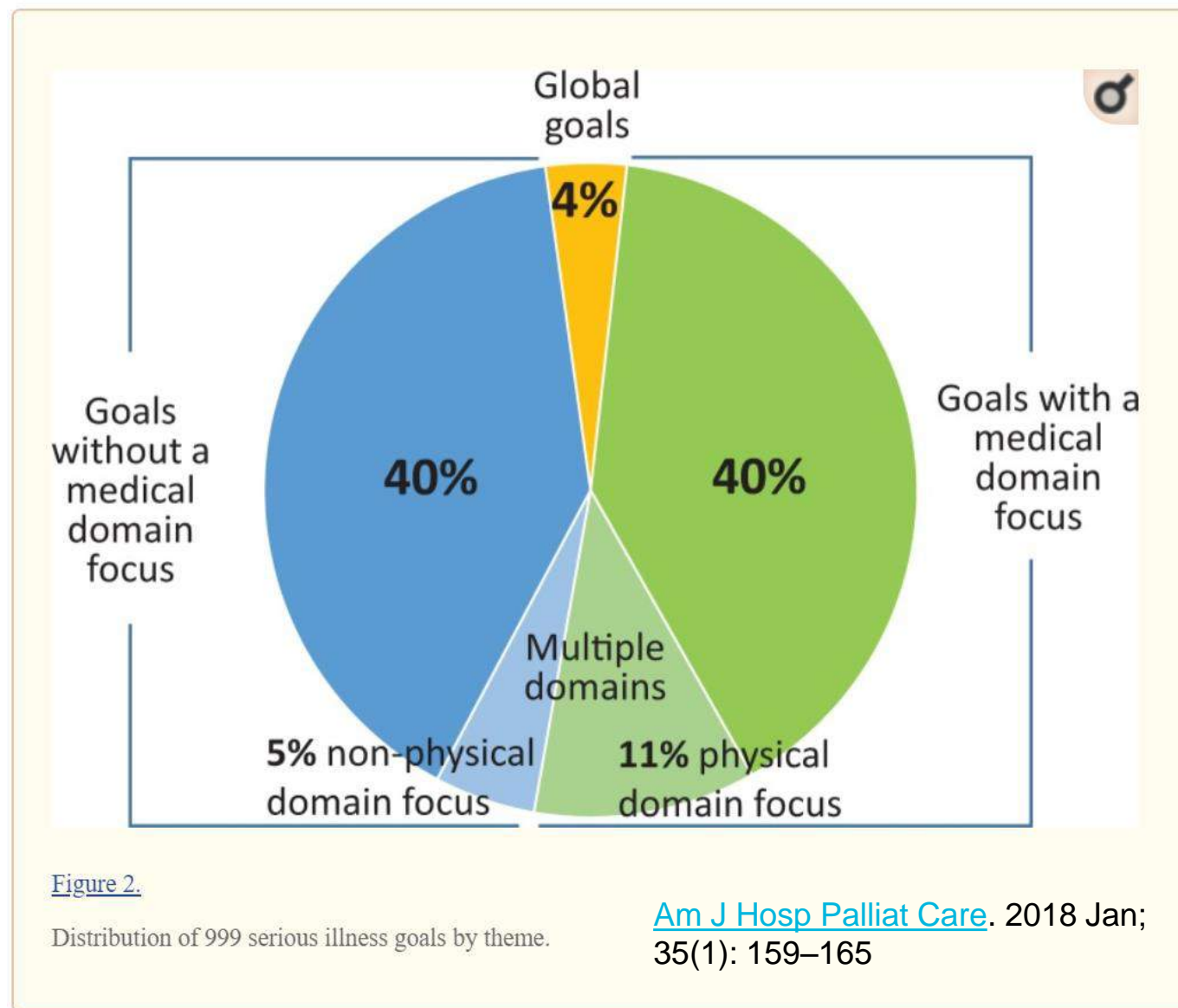
**Focus 6 Description:** "Discuss my health with family"

**Focus 7 Description:** "I don't want to go back to the hospital unless I have severe pain."

**Focus 8 Description:** "The cancer is back. I do not want to treat it."

**Focus 9 Description:** Daughter: "help to manage mom's health"

**Focus 10 Description:** Daughter: "plan for future needs"



# Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness

- Medical goals described activities that promoted change in physical and cognitive well-being or health.

- Medical goals were attributed to the physical domain and reflected desires for completing treatment plans to cure or arrest a medical condition.

- Some goals, such as “reduce Hemoglobin A1c and lower my high blood pressure,” were very specific to controlling and managing medical conditions.

- Goals related to symptom reduction, revealed patients’ desires to feel better and reduce symptoms.

- Nonmedical goals reflected other aspects of whole person and were coded in terms of the following domains:

- social (9%)

- ethical (7%)

- family/caregiver (6%)

- financial/legal (5%)

- psychological (5%)

- housing (3%)

- legacy/bereavement (3%)

- care at the EOL (1%)

- spiritual (1%)

- culture (0%)

## ACCF 2012 Health Policy Statement on Patient-Centered Care in Cardiovascular Medicine

*A Report of the American College of Cardiology Foundation Clinical Quality Committee*

### Writing Committee Members

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*"No worries, when we want your opinion, we'll give it to you"*

